

CONFERENCE REPORT

The International Summit on Health Benefits of Physical Fitness for People With Down Syndrome: Current Science, Gaps, Priorities, and Research Opportunities

Nicolas M. Oreskovic^{1,2}  | Greg Austin | Brendan Aylward | Pieter Boer³ | Véronique-A Bricout⁴ | Nashwa Cheema⁵  | Amit Das⁶ | Bo Fernhall⁷ | Richard Fleming⁷  | Carolina Florez¹ | Dan Gordon⁸ | Alexa Gozdiff Spognardi¹  | Thessa Hilgenkamp⁹  | Hampus Hillerstrom⁶ | Christopher T. Joyce¹⁰ | Don Keiller⁸ | Lois Kelly⁶ | Josh Komyerov¹¹ | Andrew E. Lincoln¹² | Sarah Mann | Lake Murray¹³ | Kandi Pickard¹³ | Lauren T. Ptomey¹⁴ | Kieran F. Reid¹⁵ | Melissa Reilly¹ | Margot Rhondeau¹³ | Stephanie L. Santoro^{1,2}  | Heidi Stanish⁷ | Josh Tam⁵  | Amy Torres^{1,2} | Brian G. Skotko^{1,2} 

¹Down Syndrome Program, Division of Medical Genetics and Metabolism, Department of Pediatrics, Massachusetts General Hospital, Boston, Massachusetts, USA | ²Department of Pediatrics, Harvard Medical School, Boston, Massachusetts, USA | ³Cape Peninsula University of Technology, South Africa | ⁴UM Sports et Pathologies, Grenoble University Hospital, Grenoble, France | ⁵Wellman Center for Photomedicine, Massachusetts General Hospital, Boston, Massachusetts, USA | ⁶LuMind IDSC Down Syndrome Foundation, Woburn, Massachusetts, USA | ⁷University of Massachusetts Boston, Boston, Massachusetts, USA | ⁸Anglia Ruskin University, Cambridge, UK | ⁹University of Nevada, Las Vegas, Nevada, USA | ¹⁰MGH Institute of Health Professions, Boston, Massachusetts, USA | ¹¹Massachusetts Down Syndrome Congress, Burlington, Massachusetts, USA | ¹²Special Olympics International, Washington, Washington DC, USA | ¹³National Down Syndrome Society, Washington, Washington DC, USA | ¹⁴Department of Internal Medicine, University of Kansas Medical Center, Kansas City, Kansas, USA | ¹⁵Laboratory of Exercise Physiology and Physical Performance, Boston Claude D. Pepper Older Americans Independence Center for Function Promoting Therapies, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts, USA

Correspondence: Nicolas M. Oreskovic (noreskovic@mgh.harvard.edu)

Received: 25 August 2025 | **Revised:** 25 August 2025 | **Accepted:** 2 September 2025

Funding: National Down Syndrome Society, LuMind IDSC Down Syndrome Foundation, Massachusetts Down Syndrome Congress.

Keywords: Down syndrome | guidelines | health | physical activity | physical fitness

ABSTRACT

The summary paper reports on and highlights the scientific discussions and development process for new expert-recommended physical fitness guidelines for individuals with Down syndrome that occurred at the inaugural International Summit on Health Benefits of Physical Fitness for People with Down Syndrome (ISFDS). The Summit was a two-day event held in May 2025 at the Massachusetts General Hospital in Boston that brought together leading international scientists, clinicians, self-advocates, community services and industries, and local and national advocacy organizations to discuss the latest research, therapies, and collaborative opportunities in physical fitness for individuals with Down syndrome. Day 1 focused on the current state of the science and the identification of research gaps; Day 2 featured working groups dedicated to developing collaborations, planning future research, and creating expert clinical guidelines on physical fitness in children and adults with Down syndrome using a Delphi approach.

Abbreviations: DS, Down Syndrome; ISFDS, International Summit on Health Benefits of Physical Fitness for People with Down Syndrome; MGH DSP, Massachusetts General Hospital Down Syndrome Program.

1 | Introduction

Individuals with Down syndrome (DS) experience unique physiological characteristics, including hypotonia and ligamentous laxity (Bertapelli et al. 2016), which contribute to delayed motor development, poor posture, difficulties with balance and coordination, and reduced proprioception (Rezaee et al. 2025). In addition to low muscle tone, chronotropic incompetence (Merzbach et al. 2023; Guerra et al. 2003), autonomic dysfunction (Frank et al. 2023), and reduced aerobic capacity (Fernhall et al. 2009) can also collectively contribute to significantly lower levels of physical fitness and physical activity throughout the lifespan (Ballenger et al. 2023). Muscular strength, particularly in the lower extremities, is crucial for daily activities, and heightened adiposity, reduced bone mineral density, and diminished lean mass also contribute to lower cardiorespiratory fitness (Stojanović et al. 2025). In combination with environmental and social barriers (Love and Agiovlasitis 2016; Shields et al. 2013), these physiological differences result in low participation in moderate-to-vigorous physical activity (Covain et al. 2023) and a heightened risk for obesity (Pitchford et al. 2018), insulin resistance (Bricout et al. 2008), sleep apnea (Nguyen et al. 2021), and other cardiometabolic conditions (Covain et al. 2023).

Structured physical activity programs have shown promise in improving cardiorespiratory fitness, muscle strength, balance, and functional mobility in individuals with DS (Hardee and Fetters 2017). However, there is currently no consensus on optimal intervention design, frequency, intensity, or duration (Ballenger et al. 2023; Muñoz-Llerena et al. 2024). Emerging research suggests that physical activity may positively influence cognitive function and offer neuroprotective benefits (Ptomey et al. 2018), particularly in the context of Alzheimer's disease, a condition that affects nearly 90% of individuals with DS by the end of life (McCarron et al. 2017; Hithersay et al. 2019). Studies have shown that exercise can enhance neural glucose metabolism, improve neural processing efficiency, increase neural excitability, enlarge hippocampal volume, and promote neuroplasticity (Duan and Li 2025). However, overall, the evidence remains limited and inconsistent (Merzbach et al. 2023; Frank et al. 2023).

Significant gaps remain in understanding how to adapt and tailor fitness and exercise interventions to meet the specific physiological responses of individuals with DS (Boer and Moss 2016a; Hilgenkamp, Beck, et al. 2024; Kashi et al. 2023). These include attenuated heart rate and blood pressure responses, impaired autonomic regulation (Fernhall et al. 2013), and differences in energy metabolism (Fernhall et al. 2009). Long-term studies are scarce, and there is limited translation of existing research into scalable, community-based models that can be broadly implemented (Hardee and Fetters 2017). In addition, there are currently no existing clinical recommendations for physical fitness specific to people with DS to guide clinicians, patients, and families.

2 | Methods

In May 2025, the Massachusetts General Hospital in Boston, USA, hosted an International Summit on the Health Benefits of Physical Fitness for People with Down Syndrome (ISFDS). Funding support for ISFDS was provided by three not-for-profit organizations: the National Down Syndrome Society, the Massachusetts Down Syndrome Congress, and LuMind IDSC Down Syndrome Foundation. This two-day scientific meeting on May 15 to 16, 2025, aimed to bring together leading scientists and clinicians from around the globe to discuss the latest research and therapies, promote knowledge exchange across the scientific community, and forge new collaborative opportunities in the field of physical fitness for individuals with DS (Figure 1). The Summit featured 2 days of engaging presentations (Figure 2), discussions, and collaborative planning. Day 1 focused on the current state of the science on physical fitness in people with DS, with presentations by Summit participants (see Abstract Information Presented by Summit Attendees section below), along with a participatory process for identifying gaps in the science and research in physical fitness in DS. Day 2 consisted of working groups dedicated to fostering translational research in fitness in Down syndrome by formulating collaborations, bridging basic science research with clinical research and through to clinical care and outcomes, planning for future research, and the initial development of expert recommendations on physical fitness in DS. The Summit featured a diverse panel of international experts

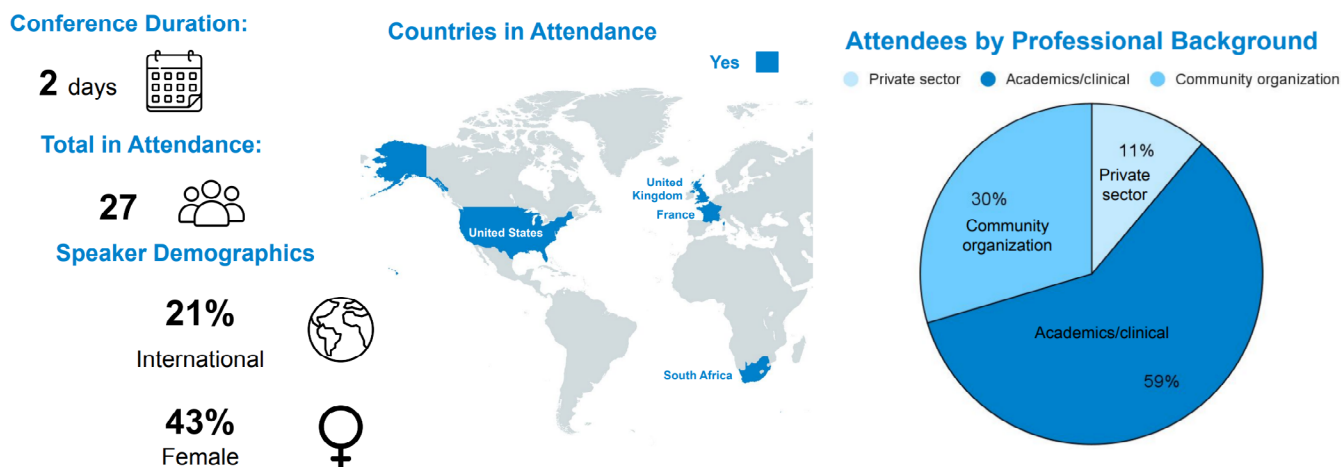


FIGURE 1 | Demographics of the 2025 International Summit on the Health Benefits of Physical Fitness for People with Down Syndrome (ISFDS).

Assessing Activity and QOL	Exercise Interventions	Functional Fitness & Aging	Exercise Physiology	Inclusive Fitness
Physical activity levels, preferences, barriers, and the role of provider counseling in promoting activity among individuals with DS.	Remote exercise program aimed at preventing Alzheimer's disease in adults with DS.	Muscle power as a key determinant of function and proposed interventions to support independence in aging adults with DS.	Physiological contributors to low aerobic capacity in DS, including fat mass, insulin resistance, and hormonal imbalances.	Insights from building an inclusive physical therapy practice for individuals with disabilities, including DS.
The Down Syndrome Health Measure (DSHM), a survey tool to assess health and physical activity impacts on quality of life.	MinDSets study data on how exercise impacts cognitive and physical function in adults with DS.	Longitudinal findings of age-related fitness declines and validated a DS-specific assessment tool.	Autonomic dysfunction—low HR, blunted sympathetic response—as a central factor in reduced exercise capacity.	AdaptX's model integrating clinical PT into inclusive fitness programs and community partnerships.
	Evidence on exercise benefits and proposed a gene-exercise study to explore personalized interventions.	The Mann Method PT framework to address musculoskeletal, vestibular, and endurance challenges across the lifespan.	Exercise physiology and cardiovascular considerations in adults with DS.	The impact of physical activity, particularly Special Olympics on the life of a person with DS.
			Photobiomodulation therapy as a novel tool for enhancing muscle repair and function.	

FIGURE 2 | Conference presentations by topic.

in physical fitness in DS, exercise physiology in DS, and related scientific fields of study.

3 | Abstracts of Information Presented by Attendees at Summit by Topic

3.1 | Assessing Activity and Quality of Life

Nicolas Oreskovic, MD, MPH (USA) presented on physical activity in children and adults with DS. He presented on physical activity patterns, preferences, barriers, and counseling. He described methods for collecting objective physical activity in DS, including objective accelerometry measurement, and reported on low health-enhancing physical activity and high sedentary time levels in DS, presented data on physical activity intensity levels by age, sociodemographic, and weight categories (Oreskovic et al. 2020). He shared findings on common caregiver-reported physical activity preferences in individuals with DS, including dancing and walking, along with common caregiver-reported DS-specific physical activity facilitators, including enjoyment, rewards, and exercise partners, and barriers, including boredom and transportation (Oreskovic et al. 2022; Schultz et al. 2023). He then reported on the difference in the prevalence of physical activity counseling by primary care physicians and DS-specialists (Harisinghani et al. 2024). Oreskovic ended the talk by discussing the importance of understanding physical activity levels in individuals with DS, given the role of physical activity in health and common co-occurring medical conditions, quality of life, and healthy aging in DS (Oreskovic et al. 2023; Hendrix et al. 2021).

Stephanie Santoro, MD (USA) gave a talk on measuring health using surveys in DS, and presented on the Down Syndrome Health Measure (DSHM). She summarized her research to develop a survey item pool including: focus groups and expert panels (Santoro, Cabrera, Haugen, et al. 2023), development of a conceptual model (Santoro, Cabrera, Co, et al. 2023), and cognitive interviews. She described recruitment efforts (Shaffer et al. 2025; Witt et al. 2025) to survey 542 caregivers of individuals with DS age 0 to 21 using the novel DSHM. Analysis shows the DSHM to be population-specific, content-valid with acceptable internal consistency and test-retest reliability. Dr. Santoro highlighted that the DSHM is freely available to researchers and clinicians who wish to study health in individuals with DS (Santoro, Baker, Blake, et al. 2023), and she can be contacted (ssantoro3@mgh.harvard.edu) for more information, for access to the DSHM and associated scoring guide.

3.2 | Exercise Interventions

Lauren Ptomey, PhD, RD, LD (USA) presented on remote exercise for the prevention of Alzheimer's Disease in adults with DS. She reviewed that Alzheimer's disease (AD) is the leading cause of death in individuals with Down syndrome (DS) (Fortea et al. 2020; Iulita et al. 2022), and presented evidence indicating that participation in moderate-to-vigorous physical activity (MVPA) may prevent or delay the onset of AD (Ptomey et al. 2018; Fleming et al. 2021; Pape et al. 2021). She shared findings on a randomized study evaluating the feasibility and potential effectiveness of using remotely delivered home-based group exercise to increase daily MVPA in adults with DS prior to the onset of AD (Ptomey et al. 2020). She presented successful

techniques the study used to maximize participant retention and attendance at exercise, support, and education sessions. Ptomey reviewed how these study results support the finding that patients who engage in remotely delivered group exercise 3 days a week, in conjunction with twice monthly support and education, are feasible and potentially effective for increasing daily MVPA and cardiorespiratory fitness to a level that may impact health and cognitive parameters in adults with DS.

Dan Gordon, PhD (UK) discussed the role of exercise in physical and cognitive attributes in adults with DS and presented findings from the MinDSets Study. He reviewed the aims of the MinDSets study, namely to explore the benefits of prescribed exercise on physical, cognitive, and psychosocial health benefits for adults with Down Syndrome (Merzbach et al. 2023). He described how the collaborative study MinDSets brought together partners from the Canadian Down Syndrome Society (CDSS), Google, FitBit, Posit Science, FCB, and Bliss to establish a multi-centre study (Merzbach et al. 2024). Gordon presented on study enrollment, which included 83 participants from five continents, and on the physical fitness and self-reported study outcomes, which included a modified version of the six-minute walk test, general self-efficacy, satisfaction with life, short term memory function, sustained attention, selective attention, and perception of mood states. He presented on the study's use of a novel, bespoke, computer application used to measure self-reported outcomes. He reviewed the study interventions, which included walking/jogging sessions and cognitive training, and then presented the significant study findings, which included improvements in the six-minute walk test, vigilance, selective attention, and mood, including sustained longer-term improvements at 18 months. Gordon discussed how the changes may be attributed to changes in optic flow and the need for greater spatial awareness and short term memory processing when undergoing exercise. He concluded by calling for future research into assessing the impact of prescribed activity loads on cognitive function and the genetic components contributing to these responses.

Don Keiller, PhD (UK) presented on the effects of prescribed exercise on physical and cognitive health in individuals with Down syndrome (DS). He reviewed the limited existing research on exercise-related benefits for people with DS, including improvements in fitness, cognition, and well-being, based on a literature search (Cain 2026). He noted gaps in data on types of exercise and regional differences in access, which are being explored through an international questionnaire (Cain 2026). Keiller shared findings on individual variability in exercise response, influenced by genetic factors (Chung et al. 2023), and highlighted that many relevant alleles are located in non-coding regions of the genome (Chung et al. 2023). He emphasized the importance of gene regulation in DS (Chapman et al. 2024) and concluded with plans for an intervention study combining exercise and genetic analysis to identify genetic profiles most responsive to aerobic exercise.

3.3 | Functional Fitness and Aging

Kieran Reid, PhD, MPH (USA) presented on functional fitness in adults with Down syndrome (DS), focusing on physical impairments that limit independence and reduce quality of life. He noted

that while life expectancy in DS has improved, it is often accompanied by earlier functional decline (Shields 2021). He reviewed evidence that resistance training improves muscle strength in DS but emphasized that its impact on functional outcomes remains unclear (Shields 2021; Melo et al. 2022). Drawing from research in older adults, he highlighted muscle power as a key predictor of functional ability, noting that it declines more rapidly than strength and may yield greater benefits from targeted training (Reid and Fielding 2012; Reid et al. 2015). He proposed that evaluating muscle power impairments in DS may inform the development of more effective exercise interventions aimed at maintaining independence and enhancing quality of life.

Pieter Boer, PhD (South Africa) presented on functional fitness in adults with Down syndrome (DS), focusing on age-related declines and tailored assessment tools (Boer 2021). He described the development of a standardized functional fitness test specific to individuals with DS (Terblanche and Boer 2013; Boer and Moss 2016b, 2016c) and shared findings from a 12-year longitudinal study showing significant declines in balance, flexibility, strength, and aerobic capacity (Boer 2024). He emphasized that these declines often fall below the thresholds needed for independent living and highlighted the importance of early and ongoing physical activity. He reviewed multiple exercise interventions—such as aerobic training, interval training, swimming training, resistance training, and dance-based programs—that led to significant improvements in functional fitness and reductions in BMI (Boer and Moss 2016b; Steyn et al. 2024; Boer 2020; Boer and de Beer 2019). He also presented research validating the Test of Gross Motor Development (TGMD) for use in children with DS (Abiodun-Salawu and Boer 2025) and shared insights from the 2023 Global Games, noting unique pacing challenges in elite athletes with DS compared to those with other intellectual disabilities (Boer et al. 2025). Lastly, insights regarding a modified treadmill protocol for adults with DS (Boer 2023) and cerebral oxygenation in adults with and without DS were shared (Boer 2025).

Sarah Mann, DPT, MBA (USA) presented on physical therapy (PT) and PT-based exercise for individuals with Down syndrome (DS), emphasizing the role of evidence-based practice in program development. She introduced the Mann Method PT-Based Exercise Program, a systems-based framework grounded in the International Classification of Functioning, Disability and Health (ICF) Systems Review Model, tailored to address the unique musculoskeletal, vestibular, and motor coordination needs of individuals with DS (Mann et al. 2023). She outlined key intervention areas, including foundational strength, hip stability, visual-vestibular coordination, endurance, muscle tension, and reflex integration (Guerrero et al. 2023). Mann highlighted her team's expertise in gait analysis, orthotic recommendations, and both in-person and telehealth physical therapy (PT) services (Hilgenkamp, Lum, et al. 2024). She also shared contributions to the GiGiFIT program, which delivers PT-based fitness programming across the lifespan in collaboration with GiGi's Playhouse Inc. The Mann Method team is expanding through continuing education initiatives for PT providers working with the DS population. Mann concluded by calling for further research on musculoskeletal and visual-vestibular conditions in DS, orthotic interventions, telehealth delivery, and provider training strategies.

3.4 | Exercise Physiology

Véronique Bricout—Serrurier, PhD (France) presented on physical fitness in adults with Down syndrome (DS), drawing from lab-based studies and clinical trials. She reported that individuals with DS typically have lower fitness levels (Mendonça et al. 2010) and identified several contributing physiological factors, including dysautonomia, high fat mass, hormonal imbalances, reduced fat oxidation, and insulin resistance. She highlighted chronotropic incompetence—low peak heart rate—as a key factor limiting aerobic capacity in DS (Guerra et al. 2003), with potential links to higher cardiac risk (Day et al. 2005). She emphasized that both physiological (Barr and Shields 2011) and lifestyle factors, such as sedentary behavior, may contribute to reduced fitness (Rimmer et al. 2004). Bricout concluded by advocating for tailored physical activity programs as non-pharmacological strategies to improve health in DS, and called for further research into how exercise interventions affect long-term outcomes and quality of life.

Bo Fernhall, PhD (USA) presented on physiological mechanisms underlying reduced physical work capacity in adults with Down syndrome (DS). He focused on autonomic dysfunction, highlighting that individuals with DS consistently exhibit lower maximal heart rates during exercise (Fernhall et al. 2001), likely due to a blunted sympathetic response and reduced catecholamine levels (Fernhall et al. 2009). He shared findings from treadmill and isometric exercise studies showing lower heart rate, blood pressure, and altered parasympathetic modulation in DS compared to controls (Fernhall and Otterstetter 1985). He also discussed evidence of reduced baroreceptor function and a diminished metaboreflex response (Heffernan et al. 2005). Fernhall concluded that these autonomic impairments likely limit oxygen delivery during exercise, contributing to the low work capacity seen in individuals with DS.

Thessa Hilgenkamp, PhD (USA) summarized over 18 years of research on physical activity, fitness, and cardiovascular health in adults with intellectual disabilities, particularly DS. Her work showed that adults with DS face unique cardiovascular risks, including elevated morbidity and mortality despite some protective traits (De Leeuw et al. 2025). Low cardiorespiratory fitness, a key predictor of mortality, is consistently observed in this population, likely due to physiological barriers such as autonomic dysfunction and impaired blood flow regulation (Fernhall et al. 2013). Studies confirmed blunted vascular responses during exercise and other tasks (Mann et al. 2023). To address these challenges, a tailored physical therapy-based intervention (the Mann Method PT program) was developed (Mann et al. 2023) and demonstrated positive effects on strength, endurance, and balance in a randomized controlled trial (Guerrero et al. 2023). Dr. Hilgenkamp emphasized the importance of continued research and implementation of accessible, DS-specific exercise programs to support long-term cardiovascular health (Hilgenkamp et al. 2025).

Nashwa Cheema, PhD (USA) and Joshua Tam, PhD (USA) presented on photobiomodulation (PBM) therapy and its potential applications for muscle function. They described PBM as a non-invasive technique using red and near-infrared light

to stimulate cellular processes, reduce inflammation, and support tissue repair (De Freitas and Hamblin 2016). They reviewed animal and human studies showing that PBM may improve physical performance and reduce fatigue-related muscle damage (Ferraresi et al. 2016), though underlying mechanisms remain unclear. They shared findings from a mouse study using treadmill fatigue testing, where PBM improved performance and muscle regeneration. RNA sequencing showed increased expression of genes involved in tissue repair. They noted the lack of standardized PBM treatment parameters and highlighted the need for further research, particularly in populations with muscle dysfunction. While no PBM studies currently target physical fitness in individuals with Down syndrome (DS), early studies suggest potential cognitive benefits (Mannu et al. 2019), and clinical trials are underway (Vieira et al. 2024). They concluded by emphasizing PBM's promise as a safe, FDA-cleared, and easily translatable therapy for muscle weakness.

3.5 | Inclusive Fitness

Greg Austin, MBA (USA) talked about his experience establishing and building a business centered on providing inclusive PT options for individuals with disabilities, including individuals with DS.

Brendan Aylward and Chris Joyce, DPT, PhD (USA) discussed expanding inclusive fitness pathways for individuals with DS. Their organization, AdaptX, is a nonprofit dedicated to improving health and fitness access for individuals with disabilities through education, research, advocacy, and opportunity. Embedded within AdaptX is the Rick Hoyt Research Lab, which focuses on two key areas of clinical and translational science: (1) optimizing exercise delivery for individuals with intellectual and physical disabilities, and (2) implementing accessible, inclusive fitness environments. They shared findings from foundational studies supporting these goals and highlighted recent work aimed at advancing their mission. Their presentation opened the door to future collaborations with researchers and professionals in health and physical activity.

Melissa Reilly shared her personal story of living with Down syndrome, highlighting the role of physical activity—particularly the positive impact that Special Olympics has had on her life.

3.6 | Community and Not-for-Profit Organizations

Representatives from the National Down Syndrome Society, The Massachusetts Down Syndrome Congress, and Special Olympics presented on the role of DS organizations in supporting, funding, and collaborating on health and physical fitness research in DS as well as disseminating findings in the community.

4 | Delphi Process

To derive expert-guided clinical recommendations for physical fitness in DS, we applied a modified Delphi method based on an

iterative feedback and voting process (Adler and Ziglio 1996). We decided a priori on an 85% agreement threshold requirement to achieve recommendation status. In accordance with the Delphi method, the panel participants consisted of experts in the field of fitness in DS; the voting process was anonymous and iterative, with opportunity for feedback at each round, with anonymized analytics and feedback disseminated to all panel participants after each round of voting, and agreement on the consensus threshold requirement determined prior to the

initiation of the voting process. Twenty-three experts participated on the panel, each with the option to abstain from voting during each round on any recommendation for which they felt they did not obtain sufficient expertise to vote. The first round of in-person voting occurred during the Summit, with subsequent iterative rounds of electronic voting conducted asynchronously after the Summit conclusion. Four rounds of voting were conducted in total throughout the Delphi process to achieve consensus on all recommendations.

TABLE 1A | Recommended guidelines for promotion of physical fitness for persons with DS.

Age (years)	Category	Recommendation	Strength of evidence
5–12	Aerobic	Daily movement encouraged, with a goal of at least 30 min or more at a moderate or greater intensity	Weak to Moderate
	Muscle	Daily muscle use, including any combination of play activities, sports that use body weight, or full body exercises	Weak to Moderate
	Balance	At least twice weekly non-structured exercises, multi-component physical activities, or physical play activities	Moderate
13–17	Aerobic	Daily movement encouraged, with a goal of 30 min or more at a moderate or greater intensity	Weak to Moderate
	Muscle	At least 3 days of muscle use, including any combination of play activities, sports that use body weight, or full body exercises	Moderate
	Balance	2–3 times per week; 15–20 min sessions	Moderate
18+	Aerobic	Daily activity with a goal of achieving at least 150 min per week of moderate or higher intensity movement	Weak to Moderate
	Muscle	2–3 times per week; 2–3 sets of 6–12 repetitions at moderate to hard intensity; 30–60 min sessions	Moderate to Strong
	Balance	2–3 times per week; 20–30 min sessions	Moderate

TABLE 1B | Examples of physical fitness exercises for persons with DS by age and category.

Age (years)	Category	Examples
5–12	Aerobic	Playground activities (tag, jungle gym, hopscotch), individual sports (martial arts, swimming), team sports (soccer, basketball, kickball)
	Muscle	Bodyweight, resistance bands, light weights, obstacle courses
	Balance	Playful activities like hopping, skipping, single-leg stance, balance beam, throwing and catching
13–17	Aerobic	Running, stationary bicycle, outdoor bicycle, swimming, hiking, dance, team sports, individual sports, whole body exercise, roller skating/inline skating/skateboarding, cross-country skiing
	Muscle	Bodyweight, resistance bands, gym equipment, obstacle courses
	Balance	Tandem stance, single-leg squats, unstable surfaces, yoga, dance, circus and gymnastics activities, lateral tilts, front-to-back tilts, over-under passes with ball, throwing and catching
18+	Aerobic	Brisk walks, running, stationary bicycle, outdoor bicycle, rowing, swimming, water aerobics, interval training, dance, hiking, individual sports, whole body exercises, roller skating/inline skating/skateboarding, cross-country skiing
	Muscle	Machines, free weights, resistance bands, bodyweight
	Balance	Heel-to-toe walking, tandem stance, single-leg stance, weight shifts, balance boards, Tai Chi, adapted dance, gymnastics, Pilates, walking on low balance beam, lateral tilts, front-to-back tilts, over-under passes with ball

5 | Recommendations

5.1 | Guidelines on Fitness for Persons With DS

An output of ISFDS was the creation of a Delphi method derived expert-guided clinical recommended guidelines for physical fitness promotion in children and adults with DS Table 1A.

5.2 | Physical Fitness Activity Type Examples

Accompanying the recommended physical fitness promotion guidelines, ISFDS created an accompanying Delphi method derived expert-guided examples of physical fitness exercises for children and adults with DS Table 1B.

A major focus of the Summit was fostering new collaborations and networking opportunities to advance the science of physical fitness in DS. The Summit brought together an international group of researchers and scientists, along with local, national, and international DS organizations to drive new research in physical fitness and related fields, broaden networks, and foster new collaborations. During the Summit, attendees collaboratively worked to assess and identify gaps in the current understanding of fitness in DS and began developing novel approaches to study the knowledge gaps. These transformative collaborations underscore the importance of the Summit. The interdisciplinary engagement of clinicians, scientists, and community organizations advanced our understanding of the physiology and impact of fitness in DS, and affirmed the prioritization of patient-first research, interventions, and programming.

Acknowledgments

Artificial Intelligence (AI) tools, including NotebookLM and Google Gemini Deep Research, were used to help identify publications on the topic of physical fitness in Down syndrome, as well as to outline an initial discussion guide draft that was used during the Summit to help guide content discussion. All AI generated materials were reviewed for accuracy and modified by Summit team members (N.M.O., B.G.S., A.G.S.) prior to use during the Summit and all reviewed and modified content were then reviewed and approved by all Summit participants.

Conflicts of Interest

Dr. Oreskovic has been asked to serve as an expert witness for legal cases where Down syndrome is discussed and serves in a non-paid capacity on the Medical and Scientific Advisory Council of the Massachusetts Down Syndrome Congress. Dr. Skotko occasionally consults on the topic of Down syndrome through Gerson Lehrman Group. He receives remuneration from Down syndrome non-profit organizations for speaking engagements and associated travel expenses. In the past 2 years, Dr. Skotko received annual royalties from Woodbine House Inc., for the publication of his book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. Within the past 2 years, he has received research funding from AC Immune, and LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with Down syndrome. Dr. Skotko is occasionally asked to serve as an expert witness for legal cases where Down syndrome is discussed. Dr. Skotko serves in a non-paid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress and the Professional Advisory Committee

for the National Center for Prenatal and Postnatal Down Syndrome Resources. Dr. Skotko has a sister with Down syndrome. Dr. Santoro has received research funding from LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS within the past 2 years. She serves in a non-paid capacity on the Medical and Scientific Advisory Council and the Executive Board of the Massachusetts Down Syndrome Congress, the Board of Directors of the Down Syndrome Medical Interest Group (DSMIG-USA), and the Executive Committee of the American Academy of Pediatrics Council on Genetics. Dr. Mann is the owner of Mann Method PT and Fitness, PLLC and Mann Method Therapy Network. She is a consultant for GiGi's Playhouse and has received funding for physical therapy-based exercise program design and implementation. All other authors report no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

References

- Abiodun-Salawu, S., and P. Boer. 2025. "Effectiveness of Video Support During the Administration of the TGMD-3 on the Gross Motor Performance of Children and Adolescents With Down Syndrome." *European Journal of Adapted Physical Activity*.
- Adler, M., and E. Ziglio. 1996. *Gazing Into the Oracle: The Delphi Method and Its Application to Social Policy and Public Health*. Jessica Kingsley Publishers.
- Ballenger, B. K., E. E. Schultz, M. Dale, B. Fernhall, R. W. Motl, and S. Agiovlasitis. 2023. "Health Outcomes of Physical Activity Interventions in Adults With Down Syndrome: A Systematic Review." *Adapted Physical Activity Quarterly* 40, no. 2: 378–402. <https://doi.org/10.1123/apaq.2022-0102>.
- Barr, M., and N. Shields. 2011. "Identifying the Barriers and Facilitators to Participation in Physical Activity for Children With Down Syndrome." *Journal of Intellectual Disability Research* 55, no. 11: 1020–1033. <https://doi.org/10.1111/j.1365-2788.2011.01425.x>.
- Bertapelli, F., K. Pitetti, S. Agiovlasitis, and G. Guerra-Junior. 2016. "Overweight and Obesity in Children and Adolescents With Down Syndrome-Prevalence, Determinants, Consequences, and Interventions: A Literature Review." *Research in Developmental Disabilities* 57: 181–192. <https://doi.org/10.1016/j.ridd.2016.06.018>.
- Boer, P., J. Burns, and D. V. Biesen. 2025. "Performance and Pacing Profiles of Competitive Track Events for Elite Athletes With Intellectual Impairment With and Without Additional Significant Impairments." *Adapted Physical Activity Quarterly*. <https://doi.org/10.1123/apaq.2024-0181>.
- Boer, P. H. 2020. "The Effect of 8 Weeks of Freestyle Swim Training on the Functional Fitness of Adults With Down Syndrome." *Journal of Intellectual Disability Research* 64, no. 10: 770–781. <https://doi.org/10.1111/jir.12768>.
- Boer, P. H. 2021. *Functional Fitness for Adults Living With Down Syndrome*. AOSIS. <https://doi.org/10.4102/aosis.2021.BK252>.
- Boer, P. H. 2023. "A Slightly Adapted Treadmill Protocol for the Determination of Maximal Oxygen Uptake in Adults With Down Syndrome." *Journal of Applied Research in Intellectual Disabilities* 36, no. 5: 1162–1168. <https://doi.org/10.1111/jar.13138>.
- Boer, P. H. 2024. "Functional Fitness of Adults With Down Syndrome: A Longitudinal Study." *Journal of Intellectual Disability Research* 68, no. 3: 237–247. <https://doi.org/10.1111/jir.13107>.
- Boer, P. H. 2025. "Cerebral Oxygenation During Submaximal and Peak Exercise for Sedentary Adults With and Without Down Syndrome." *Frontiers in Physiology* 16: 1595710. <https://doi.org/10.3389/fphys.2025.1595710>.

- Boer, P. H., and Z. de Beer. 2019. "The Effect of Aquatic Exercises on the Physical and Functional Fitness of Adults With Down Syndrome: A Non-Randomised Controlled Trial." *Journal of Intellectual Disability Research* 63, no. 12: 1453–1463. <https://doi.org/10.1111/jir.12687>.
- Boer, P. H., and S. J. Moss. 2016a. "Test-Retest Reliability and Minimal Detectable Change Scores of Twelve Functional Fitness Tests in Adults With Down Syndrome." *Research in Developmental Disabilities* 48: 176–185. <https://doi.org/10.1016/j.ridd.2015.10.022>.
- Boer, P. H., and S. J. Moss. 2016b. "Effect of Continuous Aerobic vs. Interval Training on Selected Anthropometrical, Physiological and Functional Parameters of Adults With Down Syndrome." *Journal of Intellectual Disability Research* 60, no. 4: 322–334. <https://doi.org/10.1111/jir.12251>.
- Boer, P. H., and S. J. Moss. 2016c. "Validity of the 16-Metre PACER and Six-Minute Walk Test in Adults With Down Syndrome." *Disability and Rehabilitation* 38, no. 26: 2575–2583.
- Bricout, V. A., M. Guinot, P. Faure, et al. 2008. "Are Hormonal Responses to Exercise in Young Men With Down's Syndrome Related to Reduced Endurance Performance?" *Journal of Neuroendocrinology* 20, no. 5: 558–565. <https://doi.org/10.1111/j.1365-2826.2008.01695.x>.
- Cain, R. 2026. *Benefits of Prescribed Exercise on Physical and Cognitive Health for People With Down Syndrome [Unpublished Doctoral Dissertation]*. Anglia Ruskin University, School of Psychology, Sport and Sensory Sciences.
- Chapman, L. R., I. V. P. Ramnarine, D. Zemke, A. Majid, and S. M. Bell. 2024. "Gene Expression Studies in Down Syndrome: What Do They Tell us About Disease Phenotypes?" *International Journal of Molecular Sciences* 25, no. 5: 2968. <https://doi.org/10.3390/ijms25052968>.
- Chung, H. C., D. R. Keiller, P. M. Swain, S. L. Chapman, J. D. Roberts, and D. A. Gordon. 2023. "Responsiveness to Endurance Training Can Be Partly Explained by the Number of Favorable Single Nucleotide Polymorphisms an Individual Possesses." *PLoS One* 18, no. 7: e0288996. <https://doi.org/10.1371/journal.pone.0288996>.
- Covain, S., S. Baillieul, T. D. Nguyen, M. Guinot, S. Doutreleau, and V. A. Bricout. 2023. "Gender Differences, Motor Skills and Physical Fitness Heterogeneity in Adults With Down's Syndrome." *Journal of Clinical Medicine* 12, no. 4: 1367. <https://doi.org/10.3390/jcm12041367>.
- Day, S. M., D. J. Strauss, R. M. Shavelle, and R. J. Reynolds. 2005. "Mortality and Causes of Death in Persons With Down Syndrome in California." *Developmental Medicine and Child Neurology* 47, no. 3: 171–176. <https://doi.org/10.1017/s0012162205000319>.
- De Freitas, L. F., and M. R. Hamblin. 2016. "Proposed Mechanisms of Photobiomodulation or Low-Level Light Therapy." *IEEE Journal of Selected Topics in Quantum Electronics* 22, no. 3: 7000417. <https://doi.org/10.1109/JSTQE.2016.2561201>.
- De Leeuw, M. J., T. I. M. Hilgenkamp, D. A. M. Maes-Festen, P. J. E. Bindels, R. G. Elbers, and A. Oppewal. 2025. "Prevalence and Incidence of Cardiovascular Disease in Adults With Intellectual Disabilities: A Systematic Review." *Journal of Intellectual Disability Research*. <https://doi.org/10.1111/jir.13254>.
- Duan, X. L., and M. M. Li. 2025. "The Effect of Exercise on Improving Cognitive Function in People With Down's Syndrome: A Systematic Review and Meta-Analysis." *European Journal of Pediatrics* 184, no. 6: 349. <https://doi.org/10.1007/s00431-025-06178-6>.
- Fernhall, B., T. Baynard, S. R. Collier, et al. 2009. "Catecholamine Response to Maximal Exercise in Persons With Down Syndrome." *American Journal of Cardiology* 103, no. 5: 724–726. <https://doi.org/10.1016/j.amjcard.2008.10.036>.
- Fernhall, B., J. A. McCubbin, K. H. Pitetti, et al. 2001. "Prediction of Maximal Heart Rate in Individuals With Mental Retardation." *Medicine and Science in Sports and Exercise* 33, no. 10: 1655–1660. <https://doi.org/10.1097/00005768-200110000-00007>.
- Fernhall, B., G. V. Mendonca, and T. Baynard. 2013. "Reduced Work Capacity in Individuals With Down Syndrome: A Consequence of Autonomic Dysfunction?" *Exercise and Sport Sciences Reviews* 41, no. 3: 138–147. <https://doi.org/10.1097/JES.0b013e318292f408>.
- Fernhall, B., and M. Otterstetter. 1985. "Attenuated Responses to Sympathoexcitation in Individuals With Down Syndrome." *Journal of Applied Physiology* 94, no. 6: 2158–2165. <https://doi.org/10.1152/japplphysiol.00959.2002>.
- Ferraresi, C., Y. Y. Huang, and M. R. Hamblin. 2016. "Photobiomodulation in Human Muscle Tissue: An Advantage in Sports Performance?" *Journal of Biophotonics* 9, no. 11–12: 1273–1299. <https://doi.org/10.1002/jbio.201600176>.
- Fleming, V., B. Piro-Gambetti, A. Patrick, et al. 2021. "Physical Activity and Cognitive and Imaging Biomarkers of Alzheimer's Disease in Down Syndrome." *Neurobiology of Aging* 107: 118–127. <https://doi.org/10.1016/j.neurobiolaging.2021.07.016>.
- Fortea, J., E. Vilaplana, M. Carmona-Iragui, et al. 2020. "Clinical and Biomarker Changes of Alzheimer's Disease in Adults With Down Syndrome: A Cross-Sectional Study." *Lancet* 395, no. 10242: 1988–1997. [https://doi.org/10.1016/S0140-6736\(20\)30689-9](https://doi.org/10.1016/S0140-6736(20)30689-9).
- Frank, L., B. Helsel, D. Dodd, et al. 2023. "The Association Between Cardiovascular Health and Cognition in Adults With Down Syndrome." *Journal of Neurodevelopmental Disorders* 15, no. 1: 43. <https://doi.org/10.1186/s11689-023-09510-z>.
- Guerra, M., N. Llorens, and B. Fernhall. 2003. "Chronotropic Incompetence in Persons With Down Syndrome." *Archives of Physical Medicine and Rehabilitation* 84, no. 11: 1604–1608. [https://doi.org/10.1053/s0003-9993\(03\)00342-3](https://doi.org/10.1053/s0003-9993(03)00342-3).
- Guerrero, K., A. Umagat, M. Barton, et al. 2023. "The Effect of a Telehealth Exercise Intervention on Balance in Adults With Down Syndrome." *Journal of Applied Research in Intellectual Disabilities* 36, no. 2: 385–393. <https://doi.org/10.1111/jar.13068>.
- Hardee, J. P., and L. Fetters. 2017. "The Effect of Exercise Intervention on Daily Life Activities and Social Participation in Individuals With Down Syndrome: A Systematic Review." *Research in Developmental Disabilities* 62: 81–103. <https://doi.org/10.1016/j.ridd.2017.01.011>.
- Harisinghani, A., A. Torres, and N. M. Oreskovic. 2024. "Brief Report: Physical Activity Assessment and Counseling in Adults With Down Syndrome." *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics* 196, no. 1: e32066. <https://doi.org/10.1002/ajmg.c.32066>.
- Heffernan, K., T. Baynard, S. Gouloupoulou, et al. 2005. "Baroreflex Sensitivity During Static Exercise in Individuals With Down Syndrome." *Medicine and Science in Sports and Exercise* 37, no. 12: 2026–2031. <https://doi.org/10.1249/01.mss.0000179217.59831.41>.
- Hendrix, J. A., A. Amon, L. Abbeduto, et al. 2021. "Opportunities, Barriers, and Recommendations in Down Syndrome Research." *Translational Science of Rare Diseases* 5, no. 3–4: 99–129. <https://doi.org/10.3233/trd-200090>.
- Hilgenkamp, T., A. Bodde, S. Mann, et al. 2025. "Successful Online Exercise Intervention Studies for Individuals With Intellectual Disabilities Including Down Syndrome: Best Practices and Recommendations." *Journal of Applied Research in Intellectual Disabilities* 38, no. 3: e70080. <https://doi.org/10.1111/jar.70080>.
- Hilgenkamp, T., R. Lum, C. Roys, et al. 2024. "Effects of a 12-Week Telehealth Exercise Intervention on Gait Speed and Gait Deviations in Adults With Down Syndrome." *Journal of Intellectual Disability Research* 68, no. 6: 598–609. <https://doi.org/10.1111/jir.13132>.
- Hilgenkamp, T. I. M., V. D. Y. Beck, F. Azar, et al. 2024. "Measurement Protocols and Determinants of Peak Oxygen Consumption in Adults

- With Down Syndrome: A Systematic Review.” *Journal of Intellectual Disability Research* 68, no. 8: 893–915. <https://doi.org/10.1111/jir.13137>.
- Hithersay, R., C. M. Startin, S. Hamburg, et al. 2019. “Association of Dementia With Mortality Among Adults With Down Syndrome Older Than 35 Years.” *JAMA Neurology* 76, no. 2: 152–160. <https://doi.org/10.1001/jamaneurol.2018.3616>.
- Iulita, M. F., D. Garzón Chavez, M. Klitgaard Christensen, et al. 2022. “Association of Alzheimer Disease With Life Expectancy in People With Down Syndrome.” *JAMA Network Open* 5, no. 5: e2212910. <https://doi.org/10.1001/jamanetworkopen.2022.12910>.
- Kashi, A., H. Dawes, M. Mansoubi, and Z. Sarlak. 2023. Accessed July 17, 2025. “The Effect of a Physical Exercise Package on the Motor Proficiency of Students With Down Syndrome.” *Iranian Journal of Pediatrics* 33: 1–10. <https://brieflands.com/articles/ijp-120408#abstract>.
- Love, A., and S. Agiovlasitis. 2016. “How Do Adults With Down Syndrome Perceive Physical Activity?” *Adapted Physical Activity Quarterly* 33, no. 3: 253–270. <https://doi.org/10.1123/APAQ.2015-0042>.
- Mann, S., J. Spiric, C. Mitchell, and T. I. M. Hilgenkamp. 2023. “Development of a Physical Therapy-Based Exercise Program for Adults With Down Syndrome.” *International Journal of Environmental Research and Public Health* 20, no. 4: 3667. <https://doi.org/10.3390/ijerph20043667>.
- Mannu, P., M. Maiello, V. Spera, and P. Cassano. 2019. “Transcranial Photobiomodulation for Down Syndrome.” *Photobiomodulation, Photomedicine, and Laser Surgery* 37, no. 10: 579–580. <https://doi.org/10.1089/photob.2019.4675>.
- McCarron, M., P. McCallion, E. Reilly, P. Dunne, R. Carroll, and N. Mulryan. 2017. “A Prospective 20-Year Longitudinal Follow-Up of Dementia in Persons With Down Syndrome.” *Journal of Intellectual Disability Research* 61, no. 9: 843–852. <https://doi.org/10.1111/jir.12390>.
- Melo, G. L. R., S. Neto IV de, E. F. da Fonseca, W. Stone, and D. d. C. Nascimento. 2022. “Resistance Training and Down Syndrome: A Narrative Review on Considerations for Exercise Prescription and Safety.” *Frontiers in Physiology* 13: 948439. <https://doi.org/10.3389/fphys.2022.948439>.
- Mendonca, G. V., F. D. Pereira, and B. Fernhall. 2010. “Reduced Exercise Capacity in Persons With Down Syndrome: Cause, Effect, and Management.” *Therapeutics and Clinical Risk Management* 6: 601–610. <https://doi.org/10.2147/TCRM.SI0235>.
- Merzbach, V., M. Ferrandino, M. Gernigon, J. Marques Pinto, A. Scruton, and D. Gordon. 2023. “Impact of Prescribed Exercise on the Physical and Cognitive Health of Adults With Down Syndrome: The MinDSets Study.” *International Journal of Environmental Research and Public Health* 20, no. 23: 7121. <https://doi.org/10.3390/ijerph20237121>.
- Merzbach, V., M. Jewiss, A. Scruton, and D. Gordon. 2024. “The Effects of Prescribed Physical and Cognitive Exercise on Life Satisfaction, Self-Efficacy and Mood States in Adults With Down Syndrome: The MinDSets Study.” *International Journal of Environmental Research and Public Health* 21, no. 5: 610. <https://doi.org/10.3390/ijerph21050610>.
- Muñoz-Llerena, A., L. Ladrón-de-Guevara, D. Medina-Rebollo, and V. Alcaraz-Rodríguez. 2024. “Impact of Physical Activity on Autonomy and Quality of Life in Individuals With Down Syndrome: A Systematic Review.” *Health* 12, no. 2: 181. <https://doi.org/10.3390/healthcare12020181>.
- Nguyen, T. D., S. Baillieul, M. Guinot, S. Doutreleau, and V. A. Bricout. 2021. “Classification of Factors Effect on Sleep in Individuals With Down Syndrome.” *Brain Sciences* 11, no. 11: 1500. <https://doi.org/10.3390/brainsci11111500>.
- Oreskovic, N. M., S. Agiovlasitis, V. Patsiogiannis, S. L. Santoro, D. Nichols, and B. G. Skotko. 2022. “Brief Report: Caregiver Perceived Physical Activity Preferences of Adults With Down Syndrome.” *Journal of Applied Research in Intellectual Disabilities* 35, no. 3: 910–915. <https://doi.org/10.1111/jar.12979>.
- Oreskovic, N. M., N. T. Baumer, C. Di Camillo, et al. 2023. “Cardiometabolic Profiles in Children and Adults With Overweight and Obesity and Down Syndrome.” *American Journal of Medical Genetics. Part A* 191, no. 3: 813–822. <https://doi.org/10.1002/ajmg.a.63088>.
- Oreskovic, N. M., C. Cottrell, A. Torres, et al. 2020. “Physical Activity Patterns in Adults With Down Syndrome.” *Journal of Applied Research in Intellectual Disabilities* 33, no. 6: 1457–1464. <https://doi.org/10.1111/jar.12773>.
- Pape, S. E., R. A. Baksh, C. Startin, S. Hamburg, R. Hithersay, and A. Strydom. 2021. “The Association Between Physical Activity and CAMDEX-DS Changes Prior to the Onset of Alzheimer’s Disease in Down Syndrome.” *Journal of Clinical Medicine* 10, no. 9: 1882. <https://doi.org/10.3390/jcm10091882>.
- Pitchford, E. A., C. Adkins, R. E. Hasson, J. E. Hornyak, and D. A. Ulrich. 2018. “Association Between Physical Activity and Adiposity in Adolescents With Down Syndrome.” *Medicine and Science in Sports and Exercise* 50, no. 4: 667–674. <https://doi.org/10.1249/MSS.0000000000001502>.
- Ptomey, L. T., A. N. Szabo, E. A. Willis, et al. 2018. “Changes in Cognitive Function After a 12-Week Exercise Intervention in Adults With Down Syndrome.” *Disability and Health Journal* 11, no. 3: 486–490. <https://doi.org/10.1016/j.dhjo.2018.02.003>.
- Ptomey, L. T., A. N. Szabo-Reed, L. E. Martin, et al. 2020. “The Promotion of Physical Activity for the Prevention of Alzheimer’s Disease in Adults With Down Syndrome: Rationale and Design for a 12 Month Randomized Trial.” *Contemporary Clinical Trials Communications* 19: 100607. <https://doi.org/10.1016/j.conctc.2020.100607>.
- Reid, K. F., and R. A. Fielding. 2012. “Skeletal Muscle Power: A Critical Determinant of Physical Functioning in Older Adults.” *Exercise and Sport Sciences Reviews* 40, no. 1: 4–12. <https://doi.org/10.1097/JES.0b013e31823b5f13>.
- Reid, K. F., K. I. Martin, G. Doros, et al. 2015. “Comparative Effects of Light or Heavy Resistance Power Training for Improving Lower Extremity Power and Physical Performance in Mobility-Limited Older Adults.” *Journals of Gerontology. Series A, Biological Sciences and Medical Sciences* 70, no. 3: 374–380. <https://doi.org/10.1093/gerona/glu156>.
- Rezaee, A., H. Daneshmandi, H. Ramezanzade, S. Mohammadzadeh, M. Kurnaz, and M. Altınkök. 2025. “Improving Coordination, Proprioception, Balance and Motor Proficiency in Down Syndrome With Developmental Games.” *Experimental Physiology*. <https://doi.org/10.1113/EP092739>.
- Rimmer, J. H., T. Heller, E. Wang, and I. Valerio. 2004. “Improvements in Physical Fitness in Adults With Down Syndrome.” *American Journal of Mental Retardation* 109, no. 2: 165–174. [https://doi.org/10.1352/0895-8017\(2004\)109<165:IIPFIA>2.0.CO;2](https://doi.org/10.1352/0895-8017(2004)109<165:IIPFIA>2.0.CO;2).
- Santoro, S. L., S. Baker, J. M. Blake, et al. 2023. “Views on the Impact of the COVID-19 Pandemic on Health in People With Down Syndrome From Diverse Backgrounds.” *American Journal of Medical Genetics. Part A* 191, no. 8: 2045–2056. <https://doi.org/10.1002/ajmg.a.63233>.
- Santoro, S. L., M. J. Cabrera, J. P. T. Co, et al. 2023. “Health in Down Syndrome: Creating a Conceptual Model.” *Journal of Intellectual Disability Research* 67, no. 4: 323–351. <https://doi.org/10.1111/jir.13007>.
- Santoro, S. L., M. J. Cabrera, K. Haugen, K. Krell, and V. L. Merker. 2023. “Indicators of Health in Down Syndrome: A Virtual Focus Group Study With Patients and Their Parents.” *Journal of Applied Research in Intellectual Disabilities* 36, no. 2: 354–365. <https://doi.org/10.1111/jar.13065>.
- Schultz, E. E., K. Sergi, G. Twietmeyer, N. M. Oreskovic, and S. Agiovlasitis. 2023. “Factors That Influence Physical Activity in Individuals With Down Syndrome: Perspectives of Guardians and

Health Professionals.” *Adapted Physical Activity Quarterly* 40, no. 4: 587–606. <https://doi.org/10.1123/apaq.2022-0103>.

Shaffer, M., J. P. T. Co, K. Donelan, et al. 2025. “Successful (And Unsuccessful) Recruitment Approaches and Participant Loss in a Down Syndrome Survey.” *American Journal on Intellectual and Developmental Disabilities* 130, no. 2: 131–145. <https://doi.org/10.1352/1944-7558-130.2.131>.

Shields, N. 2021. “Physiotherapy Management of Down Syndrome.” *Journal of Physiotherapy* 67, no. 4: 243–251. <https://doi.org/10.1016/j.jphys.2021.08.016>.

Shields, N., N. F. Taylor, E. Wee, D. Wollersheim, S. D. O’Shea, and B. Fernhall. 2013. “A Community-Based Strength Training Programme Increases Muscle Strength and Physical Activity in Young People With Down Syndrome: A Randomised Controlled Trial.” *Research in Developmental Disabilities* 34, no. 12: 4385–4394. <https://doi.org/10.1016/j.ridd.2013.09.022>.

Steyn, E., P. H. Boer, and G. Joubert. 2024. “The Effect of a Walking, Dancing, and Strength Training Program on the Functional Fitness of Adults With Intellectual Disability: A Randomised Controlled Trial.” *Journal of Intellectual & Developmental Disability* 49, no. 2: 186–198. <https://doi.org/10.3109/13668250.2023.2260582>.

Stojanović, S., D. Rančić, T. Ilić, et al. 2025. “The Effects of Resistance Training on Health-Related Physical Fitness of People With Down Syndrome - A Systematic Review and Meta-Analysis.” *Disability and Rehabilitation* 47, no. 13: 3214–3223. <https://doi.org/10.1080/09638288.2024.2419421>.

Terblanche, E., and P. H. Boer. 2013. “The Functional Fitness Capacity of Adults With Down Syndrome in South Africa.” *Journal of Intellectual Disability Research* 57, no. 9: 826–836. <https://doi.org/10.1111/j.1365-2788.2012.01594.x>.

Vieira, W. F., D. R. A. Coelho, M. Gersten, et al. 2024. “TransPhoM-DS Study Grant Report: Rationale and Protocol for Investigating the Efficacy of Low-Power Transcranial Photobiomodulation on Language, Executive Function, Attention, and Memory in Down Syndrome.” *Photonics* 11: 670. <https://doi.org/10.3390/photonics11070670>.

Witt, M., M. Shaffer, A. Torres, and S. L. Santoro. 2025. “Research Letter: Recruiting a Diverse Cohort in Genetics Research-Reflecting on Demographic Representation in a Down Syndrome Survey.” *American Journal of Medical Genetics. Part A* 197, no. 10: e64111. <https://doi.org/10.1002/ajmg.a.64111>.